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# L i g bac i i e: c d c i g a c h d f he g- e effec f ea e f ad e ce a gi i h he ic h e

E [redacted] 1*, I. -A [redacted] 1, A [redacted] 2, [redacted] 3, [redacted] 4

**Abstract**

**Ob ec e:** [redacted]

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## Background

Very little information is available on the evolution of the use of high dose oestrogens as a treatment for tall stature in healthy adolescents. After the successful use of this treatment in children with pituitary gigantism in

Trobe University who were interested in the research and had significant experience in conducting long-term follow-up studies in women's health met with treating clinicians. Following an agreement for the need for a study and for formal collaboration, a period of intense discussion and consultation was undertaken with all parties to formulate the study design and research questions. Given their investment in the project and the sense of disenfranchisement that many treated tall girls felt from the original decision-making, Tall Girls Inc. and particularly the president, Janet Cregan-Wood, were involved from inception in the study design process. In 2000, the National Health and Medical Research Council (NHMRC) provided funding for the study (known as the Tall Girls Study).

## Study design

The study was, by necessity, designed as a retrospective cohort study. Ideally, the cohort would be comprised of all Australian women assessed for tall stature. However, the number of women who were assessed and/or treated in Australia was not known. What was known was that the private practice of one paediatric endocrinologist comprised a high proportion of treated tall girls. Meticulous records had been kept and the specialist was willing to make them available for the study. In addition, a large number of women had been assessed for treatment as adolescents but their estimated adult height did not warrant treatment or their parents elected not to have the treatment. All treated and untreated (assessed only) women were considered eligible to participate and the inclusion of untreated women provided an important comparison group of tall women who had been through similar referral pathways.

To ensure the most complete coverage possible, a number of direct and indirect strategies were used to maximise recruitment. These included having access to the private medical records of the main treating clinician so we could trace women through public records and invite them to participate in the study; having access to the mailing list of Tall Girls Inc. so we could invite women directly; advertising the study through the mailing list of a tall women's clothing company; inviting other paediatric endocrinologists who may have treated

contact then happens directly between the participant and the research team. In Australia, private practitioners are not obliged to keep records of children once they reach 25 years of age or seven years after last contact.

This provision protects privacy and trust in the doctor-patient relationship however, it also opens the possibility of gate-keeping by clinicians. This issue requires further ethical consideration as a clinician may decide the research is not appropriate, or that the patient would not be interested or that participation would not be in the patient's best interests, thus removing choice from the individual.

pack was sent. In other instances, an address was located for the parents but not the child. In this case we contacted the parents and asked them for contact details of their daughter(s) or requested that they forward to them our letter of invitation. Some parents were reticent or refused to do this as they felt it would raise issues they would rather let lie. In these instances we tried to collect limited data from the parents on their daughter's health and relationship status.

In all instances it is vital for rigorous epidemiological research that access to sources for tracing be maintained. Privacy is important; however this must be balanced with the public expectation that information is available on the long-term impact and effects of medical treatments. Studies would be unable to be conducted, or the validity of which would be compromised, if access to named or identifying data on a population-based level was not possible.

The issues outlined in the previous two sections,

particular example is the investigation of cancer clusters. Very few cancer clusters are found to be attributable to a particular cause or exposure but frequently the findings are received with scepticism. The experience of active engagement and explanation of research process and design may assist in this understanding.

## Implications

This paper has provided the social and historical context of a retrospective cohort study. Our experience with undertaking this study has implications for wider public health research. We believe active engagement with stakeholders provided a positive experience of the research process, improved the design of the study instruments and facilitated acceptance and understanding of the study find-

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